

SICKLE CELL

World Sickle Cell Awareness Day, observed annually on June 19th, serves as a crucial reminder of the challenges faced by individuals and families affected by sickle cell disease (SCD). This inherited blood disorder, prevalent in various parts of the world including Africa, the Mediterranean, Middle East, and parts of India, affects millions of people globally. At its core, sickle cell disease alters the structure of hemoglobin-the protein in red blood cells responsible for carrying oxygen throughout the body. Instead of their usual round shape, affected red blood cells become rigid and shaped like crescent moons (or sickles), which can hinder their ability to flow through blood vessels smoothly. This causes episodes of severe pain, known as crises, as well as other complications such as anemia, organ damage, and increased susceptibility to infections. The impact of sickle cell disease extends beyond physical symptoms. Individuals living with SCD often face stigma, misunderstanding, and limited access to healthcare and resources. This can lead to challenges in education, employment, and overall quality of life. Furthermore, the burden is not only on those directly affected but also on their families and communities who provide support and care.

Standardisation of Quality Health Care in Public Health System

DR J N SRIVASTAVA, DR K MADAN GOPAL, DR SWARNIKA PAL AND DR ABHAY DAHIYA

The National Health Mission (NHM) has been a significant initiative aimed at achieving universal access to comprehensive healthcare. The NHM focuses on strengthening healthcare infrastructure, enhancing human resources, and ensuring the availability of essential medical supplies, with primary focus on tribal and underserved areas. These efforts collectively reflect India's dedication to improving public health and making healthcare accessible to every citizen. Through different programmatic interventions, India has made a remarkable improvement in key indicators related to population stabilization, maternal, infant and child health and communicable diseases. The average rate of decline of such indicators in India has been higher than the global average, particularly for maternal, infant and under five mortality rates. However, country's health system is always challenged with the burgeoning population and newer diseases, variability and appropriateness of care for given clinical conditions and quality of services. Strengthening Healthcare systems and enhancing quality of care. Despite planned programmatic interventions, challenges pertaining to underutilisation of public healthcare facilities, inappropriate and/or unsafe treatment, missed diagnosis and disrespectful services, have been reported attributed to factors like poor infrastructure, shortage of human resources of health (HRIH), and sub optimal quality of care. These challenges are directly linked to unexpected, ill-timed preventable deaths, poor health, financial burden to individuals, and loss of trust in public healthcare system.

Cognizant of these issues, the Ministry of Health & Family Welfare adopted a multi-pronged strategy to timely intervene and address the challenges on priority. One of the interventions in this direction is to upgrade the facility-based specification across the levels of care in rural and urban areas through revised Indian Public Health Standards (IPHS), 2022, which provide a comprehensive framework for upgrading components of healthcare delivery system across public health facilities. A critical aspect of the IPHS guidelines is their emphasis on essential (minimum) and achievable (desirable) services. Each level of healthcare facility is required to provide a set of minimum services to ensure assured healthcare delivery. The guidelines specify standards for infrastructure, equipment, drugs, diagnostics, human resources, etc. aiding states/UTs in planning and ensuring consistent and reliable care.

The core objectives of the IPHS are multifaceted and in alignment of National goals in Health care service delivery. While IPHS focusses on improved accessibility by redesigning the population norms to establish health care facilities with a time to care approach, it also provides input for establishing a seamless system for patient referrals and ensuring that healthcare services are delivered in a patient-friendly and dignified manner with reduced financial burden to all. With IPHS providing a set of specifications for each level of care across public health facilities, MoHFW simultaneously prioritizes the need to improve the quality of care to curb inappropriate and unsafe treatment, missed diagnosis and to provide respectable care at public health institutions. MoHFW's flagship programme National Quality Assurance Standards (NQAS) has been designed and implemented to ensure that services at public health care facilities are not only safe and patient-centric, but also of assured level of quality. The initiative focusses on addressing the gaps in understanding, measuring and improving quality of health care services. Provision of quality healthcare in the public healthcare facilities is a critical aspect that impacts patient outcomes, safety, and overall patient satisfaction. It also aids in improving the health of the overall community, elevates the patient experiences, and enhances the service provider's experience by reducing the cost of care. Having assurance of availability of standardised services in public healthcare facilities increases the trust of population in public healthcare facilities, as shown by increased footfalls and better relationships with all stakeholders. NQAS implementation has also ensures the compliances of health facilities to regulatory requirements and preparedness for fire safety, etc.

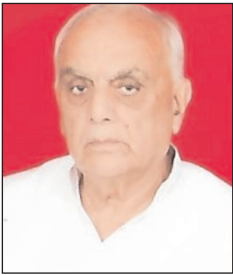
Ensuring quality in healthcare has also addressed the disparities and ensures that all patients, regardless of their background or circumstances, receive equitable care. This is crucial for achieving health equity and social justice and is aligned with government's principle of ensuring ease of living for all. Taking learnings from the recent pandemic, and preparing for any future public health emergencies, the Indian Public Health Systems, got the largest pan-India mission on infrastructure support i.e. Pradhan Mantri Ayushman Bharat Health Infrastructure Mission (PM-AHHIM). With prime focus on infrastructure and surveillance activities, and to ensure the accessibility, efficiency, effectiveness, and quality of services through cost-effective laboratory systems Integrated Public Health Lab (IPHL) was designed as a key component within PM-AHHIM. Not only these laboratories would provide rapid, reliable and accurate test results, but would also establish district and sub-district level linkages for effective diagnosis and surveillance services, thus adding on to India's step towards building a resilient health system. Having vast geographic and demographic versatility in the country and unique regional healthcare challenges, the Government of India continues to strive in achieving the universal health care through implementation of quality healthcare services which are safe, effective, patient centred, timely, efficient and equitable. To summarise, the IPHS guidelines serve as a beacon of transformation, illuminating the path to a future where health facilities are functional with a defined set of specifications, as required for service delivery at each level of care. By setting uniform standards and ensuring their implementation, the IPHS aims to make healthcare more accessible, affordable, and dignified, particularly for vulnerable and marginalized population subgroups.

In parallel, implementation of National Quality Assurance Standards in public health facilities has resulted in delivery of quality healthcare services which is vital for ensuring safe, effective, and patient-centred care, which leads to better health outcomes, enhanced patient experiences, and more efficient public healthcare system. These transformative initiatives promise to improve health outcomes, reduce the burden of preventable diseases, and foster a renewed sense of trust and reliance on the government's healthcare system.

(The writers Dr J N Shrivastava is Advisor and Dr Abhay Dahiya is consultant with Quality and Patient Safety Division and Dr K Madan Gopal is Advisor, and Dr Swarnika and Dr Arpita work as Senior Consultant Public Health Administration, National Health Systems Resource Center, MoHFW, Government of India)

Pakistan's PRO's In Kashmir Advocate -Talk to Pakistan

■ ER. P.L KHUSHU



During the latest spurt in militancy in Jammu, at places like Rajouri, Kathua, Riasi, Doda, etc, by the militants trained and armed in Pakistan, dynasty based politicians from Kashmir working as a PRO's of Pakistan in Kashmir, ever since the start of militancy in J & K, has again started crying and advocating for talking to Pakistan to avoid such militant acts by the Pakistan trained militants. There are some habitual spokes persons of Pakistan in Kashmir, probably feeling that some people of Kashmir will consider them as a diehard Muslim leaders of Kashmir, maintaining that Kashmir is still a problem between India and Pakistan. An old saying, that one should learn from one's mistakes, but such politicians are not still learning from their historic mistakes about Kashmir to en cash such a slogan for their political purposes to remain in power on their dynastic sticks for ages. What is behind such utterances which are almost anti India? Some times one feels such repeated statements can be called as seditious statements.

People of Kashmir have rejected them in the recent elections, by coming out to vote in highest percentages since decades and thus neglect them as superfluous entities with zero political values and faces. Even such dynasty based political leaders have lost miserably in the recent elections, yet, this again is not avword of caution for them that they lost their utility and worth amongst the masses of Kashmir as their representative leaders. An English proverb which says, "Once bitten twice shy". Probably they should get advised and inspired by such a saying and feel the pricks of the ground situation in Kashmir, that Jammu and Kashmir is now a full India and the people of Kashmir have endorsed the action of the Abrogation of the Article 370, by participating in bulk in the recent elections with a broad and a bold face. Even some prominent and so called eminent political faces amongst these high power politicians, calling themselves as the only political faces of Kashmir, having ruled as monarchs', while having remained as the chief ministers for longer durations in Jammu and Kashmir, have miserably lost in the recent elections.

Should they know it now that the people of Kashmir have rejected them, smelling that these politicians were actually working for their self interests and not for the welfare of the people of Kashmir.

The rut of talk to Pakistan, Pakistan is not wearing bangles , Pakistan has superior bombs and the like, often being talked about by such a regional politician, belonging to a particular dynasty, having been ruling Kashmir ever since 1947, through the various lord heads of that family, from time to time as heir apparent legacies by birth, has been blunted with a brazen slap on the face of such a politician, by the voters of Kashmir by voting in bulk and in big clusters breaking all the records of the past in such elections. It

is writing on the wall for all such politicians with dynasty bases to opt out from ruling Kashmir as their legacy and monarchy. Enough is now enough.

This repeated corroborative verbose of proposing that 'Talk to Pakistan' has been the one sentence dictum of sympathy of these leaders for Pakistan from the Indian soil and apparently will continue to use it in future too, for reasons which are obvious. Reasons are apparent. An illusory ploy by them to confuse the people of Kashmir, for their vote bank politics. Thank God they have not said so for that "Talk to Pakistan-otherwise". Alas, this "otherwise" is always visible and its repercussions are felt on ground instantaneously. Whenever such a proposition has come from such opportunist leaders of Kashmir, Pakistan in its fairness and obligatory gesture to these leaders, as is being suspected obliges the situation by creating one or the other problem in Jammu and Kashmir through the terror routes and the like.

Presuming though not conceding that enough credence should be given to their statements that India should talk to Pakistan for peace in Kashmir. But let them pronounce as to what to talk about. Should it be conveyed to Pakistan with folded hands that please pardon us and take this part of Kashmir?

That being so, why did they not do so then when they were in power in Kashmir and ruled Kashmir through dynastic limbs for decades?

Or as true politicians, in the alternative why did not they convey to Pakistan that stop the militancy in Kashmir and its devastation through terror modules, which has devastated Kashmir in each and every respect. Did they feel shy to do so for remaining in power for decades? The famous proverb goes "Better said than Done".

What to talk about and why? Pakistan started the trouble and is thus the perpetrator of the Kashmir situation, with an obsession about Jammu and Kashmir to have it, while resorting to almost four wars with India including tribal raiders attack on Jammu & Kashmir in the year 1948, without any gains by Pakistan, yet, India had to defend which it did with all its might. India has been equivocally telling Pakistan and the world over that Kashmir is an integral part of India.

If at all there is some dispute, it is about the forced invasion and the captivating of Pakistan over Indian Territory known as Pak Occupied Kashmir (POK), which is under the forced occupation of Pakistan.

In addition to such wars Pakistan in its utter frustration laid the foundation of the proxy war in Jammu and Kashmir through its trained and well equipped terrorists, apart from instilling the concept of insurgency in some of the innocent youths of Kashmir, which is now curbed to a greater extent. It is now almost the 35th year of such a proxy war through militancy in Kashmir, though restrained and curbed now to a larger extent, which Pakistan is still bent upon to rely on.

Since freedom of speech in India is available to every citizen of India, these political leaders may give all such differential statements to address their individual political constituencies. But all such political leaders are very senior persons who

have ruled Jammu and Kashmir, from time to time, they should refrain from giving such fiery statements which always jeopardizes the security scenario in J & K, resulting in loss of lives and civil disturbances of various natures, immediately after such ironical statements emanate from them.

It has tangential evidence, which gets prominence as there was a mass involvement of the people of Kashmir in the recent elections, which shows that these politically defunct leaders are now a political liability in Jammu & Kashmir; only to create noises of sorts with no material purposes. It should be an eye opener for all of them. Article 370 goes, please do not grab about it. People of Jammu and Kashmir, particularly the people of Kashmir have endorsed it, with their mass involvement in the recent elections.

They have no political standing minus the 'Gupkar-Link'. Did they ever condemn Pakistan and its terror links in Kashmir, for gruesome acts of terror and its devastation in Kashmir? In fact these tall leaders should have visited the ground locations where all such terror occur and assured the people and the administration that they condemn all such acts without any reservations. They should have visited the residences of the persons who were brutally martyred by terrorists after their fallible statements about talking to Pakistan and condemned Pakistan and its roots of terror in Kashmir, through a press conference, significantly from their "Gupkar Nest", which would show their real sympathy with the people of Jammu & Kashmir. That is why that they have no tangible following of people now.

There have been numerous attempts by India, to improve the relationship, notably the Shimla Summit, the Agra summit, and the Lahore summit. But Pakistan has never been sincere in its approach to barter peace with India for its domestic compulsions. Since the early 1980s, relations between the two nations have grown increasingly sour, particularly after Pakistan's the Siachen misadventure, and the intensification of the Kashmir insurgency in 1989. The 1999 Kargil War, was another major factor which spoiled the relations further. Certain confidence-building measures, such as the 2003 ceasefire agreement and the Delhi-Lahore Bus service, have been successful in de-escalating tensions. However, these efforts of peace by India were got impeded by periodic terrorist attacks from Pakistan. The 2001 Indian Parliament attack brought the two nations to the brink of a nuclear war. The 2008 Mumbai attacks carried out by Pakistani militants resulted in a severe blow to the ongoing India-Pakistan peace talks. Bilateral discussions between the two countries again got stalled after the 2016 Pathankot attack. In September 2016, a terrorist attack on an Indian military base, killed 19 Indian Army soldiers, the deadliest such attack in years. This attack had been orchestrated by a Pakistan-supported terrorists group, which was as usual backed by ISI of Pakistan. This attack on Indian army soldiers, sparked a military confrontation across the Line of Control , with an escalation in ceasefire violations and further

militant attacks on Indian security forces. Since 2016, the ongoing confrontation sponsored by Pakistan and its ISI, with continued terrorist attacks, has resulted in the collapse of bilateral relations. Notably, following the 2019 Pulwama attack, the Indian government revoked Pakistan's most favored nation trade status, which it had granted to Pakistan in 1996.

In November 2015, Indian Prime Minister Narendra Modi and Pakistani Prime Minister Nawaz Sharif agreed to the resumption of bilateral talks; the following month, Modi made a brief, unscheduled visit to Pakistan while en route to India, becoming the first Indian Prime Minister to visit Pakistan since 2004. Despite those efforts, relations between the countries have remained frigid, following repeated acts of cross-border terrorism by Pakistan.

These are referral incidents of terrorists attacks sponsored by Pakistan in the other parts of India, outside Jammu & Kashmir, to keep the so called Kashmir Imbroglio alive before the world community, when such incidents of terrorists attacks sponsored by Pakistan and ISI, in Jammu & Kashmir, particularly in Kashmir, are going on without break, having killed thousands of innocent people of Kashmir, the security forces and the local police personals. Militancy and terror has ruined Jammu & Kashmir and its people, particularly from the valley. Apart from that this Kashmir situation created and abetted by Pakistan has resulted in major debacles to the development of Jammu and Kashmir, apart from brain washing the misguided youth of Kashmir to take to guns to fight the Indian forces in Kashmir. It has taken a heavy toll of the youth of Kashmir, along with the devastation of so many families.

Should the political leaders recommending talks with Pakistan be reminded of the fact that more than six Lack Kashmiri Pandit families were reduced to devastation and thousand killed, their house looted and burnt, when they were made to flee from Kashmir resulting in their mass exodus from Kashmir due to pan Islamic terrorism fanned and abetted by Pakistan in Kashmir. Have they any sense of realization about this disaster of their fellow brothers the Kashmiri Pandits. Have they ever condemned Pakistan and their terror hubs in Kashmir about it? These political leaders should understand that while living in ivory towers of Gupkar, they should stop giving such sermons of talking to Pakistan which is nothing but rubbing salt on the bleeding wounds of the displaced Kashmiri Pandits. Let them stop it somewhere. They had their inning, let them take rest now in the golden nests of Gupkar, the "Acquired Gifts of Nature".

The significant issue which India has with Pakistan is that it should handover the POK to India immediately without bragging much, when the political leaders arguing for talking to Pakistan should in a plan language convey to Pakistan that handover POK to India. That it is the only solution. Let nobody remain in any dilemma.

(The author is a chartered consultant civil engineer, who loves his mother land the union territory of Jammu & Kashmir).

World Autism Pride Day

Autistic individuals are still marginalized

■ SURJIT SINGH FLORA

Communication entails sharing sentiments, likes, and dislikes. A person who cannot accomplish this is antisocial. Not everyone who does this is antisocial; autism can make communication difficult. In this situation, we need to have correct knowledge about people before making an opinion.

Every year on June 18, World Autistic Pride Day is a proud celebration of autistic people. We celebrate World Autistic Pride Day to acknowledge the significant contribution of autistic individuals in fostering positive change within society.

This year, 2024, the theme for World Autistic Pride Day is "Taking the Mask Off," which promotes the idea of autistic individuals embracing their true selves-their innate behaviors, preferences, and ways of engaging with the world.

This theme emphasizes the need for the general public to embrace and welcome autistic people into work and art. We are also emphasizing supportive laws that reduce society's receptivity to autistic individuals.

Indeed, there is no issue with awareness. The way some people define "awareness" is disheartening. That and awareness don't demand much from people. It's simple to encourage others to be mindful of or accepting of you. It can be challenging to convince others to recognize the importance of human rights and equal access in society. Reaching the latter goal necessitates more than just awareness.

Brazil celebrated its first Autistic Pride Day in 2005, reports said. Many accounts credit Gareth and Amy Nelson with making the day. In 2005, Aspires for Freedom, a Brazilian initiative, raised autism awareness and highlighted the similarities and contrasts between people with the disease. Autism has become a worldwide phenomenon over time. Autism Pride Day is essential because it raises awareness of autism's challenges. pick up Autistic children have brain development issues. To live, they require constant assistance. A sickness of the mind. To counteract this, we should respect and care for autistic people. Celebrating this day should give autistic people equal chances.

Autism is neurodevelopmental. The disease is referred to as 184 Autism Spectrum Disease. Neurodevelopmental disorders occur when genetic or environmental factors impair brain development. Children usually have this condition, although it might go undetected.

Autism spectrum disorder is one of several neurodevelopmental disorders. Autism spectrum disorder impairs communication. Patients with this condition behave repetitively. This disorder hinders language and communication. It is a complicated developmental impairment that occurs in the first three years of life. Autism is not a mental impairment; people with autism may thrive in art, music, and literature.

Not hearing someone call your name or responding slowly can be frustrating.

Repeating the same phrase over and over again, or performing repetitive movements such as hand flapping, back and forth, or snapping fingers,

People have a limited interest in interacting with others, and their sensitivity to sensory stimuli like sound, smell, color, and light can either increase or decrease, causing them to become upset by slight changes in their routine.

World Autistic Pride Day highlights the need to support and improve the quality of life of people living with autism so that they can live full and meaningful lives as an integral part of society.

World Autistic Pride Day aims to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with autism, as well as to promote their inherent dignity and respect.

Scientists believe that genetic or environmental factors may link to autism, although the exact cause remains unknown. There is no cure for autism spectrum disorder; but language therapy, occupational therapy, educational support, and many other methods can help children with autism and their parents.

Autism is prevalent all over the world. A report predicts that by 2020, autism will impact approximately 75 million individuals worldwide.

Autism affects more people globally than diabetes, cancer, and AIDS combined. Autism affects 100 out of 10,000 children globally. Many

studies show that autism is more common in boys than girls. This condition affects 80% of males.

Autistic children are difficult to parent. Their caregivers must remain optimistic and take care of themselves. Autism lasts a lifetime. The youngster may always require extra care and help.

It's important to recognize that not all individuals on the autism spectrum are either intellectually disabled or possess extraordinary STEM abilities. Each individual possesses unique strengths, weaknesses, interests, sensitivities, and goals. It is important to have a range of options available that cater to different needs, rather than being limited to either complete dependence on NT care workers or having no support at all based on IQ levels. Unfortunately, that doesn't provide any assistance whatsoever.

Given the unique support needs and goals of individuals on the autism spectrum, it is crucial to establish a comprehensive system of support options. This will enable us to flourish, regardless of the challenges associated with our specific form of autism. It is crucial for neurotypical individuals to invest time in listening to and understanding us as individuals, in order to build a comprehensive system of support options. Many times, individuals who possess the ability to clearly articulate their life goals and the necessary steps to achieve them are unfortunately overlooked by those who do not understand their unique perspectives. This lack of understanding often results in conflicts and failures as well-intentioned individuals attempt to guide them down paths that may not align with their true needs. Individuals with intellectual disabilities and autism often face challenges in expressing their wants, needs, and feelings. Unfortunately, they are sometimes treated with little regard, similar to how toddlers are treated. Their protests about the direction they are being taken are often ignored, leading to situations where well-meaning parents or guardians unknowingly subject their loved ones to abuse. In these cases, the cries of protest are dismissed as mere reluctance to leave the house. Unfortunately, you have no choice but to go out.

There is a significant issue with the lack of awareness and understanding between neurotypical individuals and those on the autism spectrum. This problem arises from neurotypical individuals relying on their inclination to quickly judge people and situations, rather than taking the time to truly listen, observe, and comprehend the actual circumstances. Neurotypical individuals are often raised with the belief that their instincts about the world and the people in it are consistently accurate. This notion is further reinforced by their ability to effectively understand and interpret other neurotypical individuals who share the same cultural background and social class. It can be disheartening to feel that listening to and getting to know others on a personal level is often seen as unimportant in a world where we are taught to assume that everyone thinks the same and has similar social and emotional cues. Is there someone who is reluctant to engage in an activity that you deem significant? They seem to lack motivation. Would this grown-up really choose to have a cartoon show on their iPad for their imaginary deserted island? They seem to lack maturity. This individual is attempting to articulate their perspective. They are simply fabricating excuses. Empathy and understanding are not valued, while superficial empathy and hasty assumptions are praised.

However, autism symptoms lessen with age. This will allow them to live normal lives in the future. Thus, parents and society must adapt to autistic children's shifting requirements. Society needs to rethink its view of autism. We must show love and care for autistic children and adults, enabling them to lead normal lives.

Sadly! Until now, there has been widespread acceptance of efforts to raise awareness for autistic people. I have yet to witness any "awareness" campaign that has truly made a positive impact on the lives of individuals on the autism spectrum. We only experienced acceptance when we actively advocated for it, alongside our efforts for inclusion and integration.

Simply being aware of autism is not sufficient. It was never the case.

(The writer is a veteran journalist and freelance writer based in Brampton).